Health within Illness among Persons living with Chronic Obstructive Pulmonary Disease

B. Leonard and M. Clark

Abstract— The purpose of this descriptive qualitative study is to explore perceptions of health within illness, a health strategy used by persons with chronic obstructive pulmonary disease (COPD) to maintain their quality of life. A convenience sample of 11 community-dwelling, English-speaking adults with COPD was recruited from the Southwestern United States. The study was conducted in the homes of the participants. Naturalistic inquiry using content analysis and constant comparative techniques was used to analyze the transcribed data. Five conceptual categories emerged in the final stage of analysis that provided answers to the research questions from the perspectives of the participants. The categories were: (a) Cut Off from Life, (b) Health is Everything, (c) Making the Best of It, (d) Living with It, and (e) Breaking the Cycle. Each of the categories was inducted from emergent themes and clusters of data that represented the participants' descriptions of living with COPD. The findings of this study highlight strategies and practices portrayed by the participants to promote their health despite suffering from a serious illness. Data from the study participants suggest the management of COPD is a complex process that requires considerable flexibility, creativity, and resilience to achieve a sense of health within illness. The study highlights important ways to improve self-care among COPD sufferers on how to manage this chronic illness beyond a trial and error process.

Keywords— sick role; Naturlistic; qualitative; COPD; Health within Illness

I. Introduction Health within Illness

Most studies about chronic obstructive pulmonary disease (COPD) have focused on the illness components and the difficulties of living with chronic dyspnea, such as loss of confidence to perform activities, anger, low self-efficacy, and fear **[1-7]**. Few research studies have investigated ways people living with COPD manage their daily activities to enhance their physical and emotional wellbeing. This information is critical because it helps to explain the overall concept of health despite the severity of illness. Although illness and health have been studied as separate entities, the perspective of health within illness adds a new dimension to assist with our understanding of illness. This concept is a novel way to conceptualize health and health theory development. Also, including a health within illness view highlights how "the experience of illness can accelerate personal growth through increased awareness and transformational change (**[8],** p.24)"**.**

Moch **[8]** has been a pioneer in conceptualizing health within illness. The concept is based on the idea that illness presents new opportunities for personal growth, as opposed to the traditional view where personal energy is expended in eliminating or fighting the illness. This innovative perspective of health may enhance our knowledge of the human potential to heal when faced with a chronic illness. Moch postulates that health within illness presents people with a unique opportunity to find meaning in life "through connectedness or relatedness with the environment and/or awareness of self during a state of compromised well-being (**[9]**, p. 305) This is important because COPD is one of the leading causes of morbidity and mortality worldwide **[10]** and substantially affects the life quality of those suffering from this disease.

People with COPD often modify their lifestyles to accommodate feeling short of breath. Nevertheless, many consider themselves healthy despite the fact that they have an illness for which there is no cure **[11-13].** Since the changes in lung function occur slowly, many people do not realize they have a respiratory problem until the middle to late decades of life **[14].** Frequently, people seek help from their primary care providers only after the disease is in its advanced stages.

A. Chronic Obstructive Pulmonary Disease (COPD)

More than 10,000 people die from COPD each year (in the United States), making it the third leading cause of death in the United States 2008 **[15]**, and by 2020 it is projected to be ranked as the fifth cause of death worldwide **[16]**. Approximately 12 million Americans have been diagnosed with COPD, and 24 million may have the disease but have not been diagnosed **[17].** The disease has a tremendous impact on health care cost. In the United States alone, the direct and indirect costs approach $50 billion annually **[18].**

B. Health within Illness

Moch's **[9]** research on Health within Illness focused on breast cancer survivors. Through her studies, she identified four essential components based on findings from several research studies. The first component of the illness experience may be characterized as a favorable time for growth experiences as described in much of the crisis literature **[19,**

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20]. During the second component individuals work to increase the meaningfulness of the illness by redefining their outlook on life **[21-26].** Also, events or people may take on a new sense of purpose or increased significance **[2, 25, 27-29].** A third component involves a sense of connectedness that occurs through the interaction with others, feelings about their environment, or finding relevance through spiritual connections **[25, 27, 29-31].** The fourth component is finding awareness of one's self or self-knowledge. In crisis and illness, people can become more sensitive to their bodies and through this awareness find ways to improve their experience of health. In this process, they also redefine their criteria of wellbeing **[32-35].**

In summary these four components portray health within illness as a transformational process that occurs during a state of compromised well-being. For this study, health within illness is defined as a transformational process that can expand the human potential necessary to accelerate personal growth while living with chronic illness.

II. AIM

Earlier research on people living with COPD focused on illness and related disabilities and ignored strategies people used to improve their sense of wellbeing when faced with a chronic illness. In this study, individuals were allowed to describe their daily lives from a health within illness perspective. This exploration into how people maintain their health despite the chronicity and severity of their illnesses contributes to nurses' understanding of health within the healing paradigm.

Research Questions. The purpose of this investigation was to answer the following research questions:

1. How do persons with COPD describe their experiences of health within the context of living with a chronic illness?

2. What practices and strategies do persons living with COPD use to promote their health and achieve maximum function within the limitations imposed by their chronic illness?

III. METHOD

This was a qualitative study with a convenience sample of 11 English-speaking, community-dwelling adults with COPD recruited from the Southwestern United States. The research questions followed a semi-structured interview guide developed by the researcher and all interviews were audiotaped. The interview guide helped the interviewer to consistently elicit health and healing strategies that persons with COPD use in their everyday lives. The first author as the principal investigator conducted the interviews, and each participant was initially interviewed for 60 to 90 minutes. Follow-up interviews confirmed or modified data gathered in the first interview to ensure its validity.

IV. PARTICIPANTS

A letter introducing the study was sent to participants recruited from two previous COPD studies [36, 37]. Before the interview, participants signed an IRB-approved consent form. All had a known primary or secondary diagnosis of COPD, were between the ages of 40 and 80 years of age, were able to speak English, and lived within the southwestern region of the United States. The study group consisted of five males and six females. Most were elderly (mean age 67 years, range57 to 77 years), married, and living with their spouse. Sixty-four percent were White non-Hispanic (n = 7), and 36% (n = 4) described themselves as Black. The number of years the participants had been diagnosed with COPD was 6.4 (range 1 to 18 years).

V. DATA COLLECTION

The study was conducted through personal recorded interviews, and the length of the interview varied according to the patient's responses. Field notes were also taken during the visit to document information on the environment following guidelines of "Naturalistic Inquiry" [38]. Field notes provided insights on some of the statements that were made during the interview and on personal reflections of participant descriptions. In addition to answering the interview questions, each participant filled out a demographic form. The recorded interviews were transcribed verbatim and a code number assigned to the transcripts and the recordings. All references to the participant's name were removed from the transcript to maintain confidentiality.

VI. DATA ANALYSIS

The principal investigator transcribed the interviews and used the field notes to help confirm the data's dependability. The principal investigator validated the data through multiple interviews and evaluated it for stability, consistency, and dependability. The interviews were analyzed by content analysis and constant comparative techniques using a constructivistic/naturalistic approach as described by Lincoln and Guba [38]. This approach consists of four elements: (a) unitizing the data; (b) emerging category designation; (c) analyzing negative cases; and (d) bridging, extending, and surfacing the data [39]. The fourth element is often completed between periods of data collection. Interpretation is based on the understanding that the data collected are trustworthy. The materials were subjected to a comprehensive check with each participant. A committee of expert reviewers also performed an external audit to resolve differences in opinion or clearly explain differences in the analysis.

VII. FINDINGS

Two major constructs: Changes of Outlook on Life and Patterns of Health within Illness, emerged as the overall constructs of the study. From these two constructs, five conceptual categories evolved in the final stage of analysis.

These categories provide answers to the research questions from the perspectives of the participants. The categories were labeled: (a) Cut Off from Life, (b) Health is Everything, (c) Making the Best of It (d) Living with It, and (e) Breaking the Cycle. Each of the categories was inducted from emergent themes and clusters of data that represented participants' descriptions of living with COPD (Table 1).

Table 1: Summary of the Findings: Constructs and the five Categories describing the data analysis of the study.

CONSTRUCT Changes of Outlook on Life	**CONSTRUCT Patterns of Health within Illness**			
Category I	***Category II***	***Category III***	***Category IV***	***Category V***
Cut off from Life	**Health is Everything**	**Making the best of It**	**Living with It**	**Breaking the cycle**
Transformed -Useless -Isolation -Obstacle	*Health is worth more than any Diamond* -Don't appreciate health until your sick -Being able to do -Capable of doing things -A sense of well-being -Not feeling sick -Having your psychology together…	*Tolerance* No physical healing Learning to accept Non-acceptance Cope day-to-day Endurance	*Day-to-Day Thing* Good Days/Bad Days -Illness in the background Immersed in the illness	*Trying to Maintain* -Exercise -Meditation -Prayer -Relaxation -Leave cigarettes alone
Powerless Knocked down Loss of lungpower -No energy -Spinning your wheels	*Feel Healthy some Days* -Feeling healthy within the illness	*Hopes forHealing* -Miracle	*Any Day could be the Day* -Uncertainty	*Knowing the Limits* Stop when breathing hard -Avoidance of environmental triggers -Nutrition and weight
	Feeling Connected Family members and friends -Doctor's influence -Nurse's influence	*Maintaining Independence* Do for yourself	*Dying like the Others* -Knowing what will happen -Made the wrong choice -Own fault	*Forgetting the Illness* -Keeping active… -Keeping occupied Work
		Deeper Insights -Finding personal meaning -Significance of faith	Getting Through -Looking ahead	Maintaining the Routine -Prescribed breathing enhancers Supplemental Oxygen -Mood enhancers… -Herbal breathing enhancers
				Doing what You have to do -Access to care -High cost of health care Technology versus personal need for emergency treatment -Put on the list for social services

The first category under the first construct "Changes of Outlook on Life," is Cut off from Life, and portrays what life has been like for the participants with COPD. It answers both research questions by illustrating the participants' perceptions of their illness and explaining how their lives have been changed by it. The second construct, Patterns of Health within Illness, highlights categories two through five (see Table 1) and answers both research questions through the participants' descriptions. Specifically the categories under second construct, *Health is Everything* and *Making the Best of It*, present data to answer research question one (How do COPD patients perceive and describe their experiences of healing and health within the context of living with a chronic illness?). The second research question (What practices do COPD patients use to promote their health and achieve maximum function?) is answered by data organized in the following three categories (category II, III and IV) under the second construct: *Making the Best of It*, *Living with It*, and *Breaking the Cycle* (see Table 1). These categories represent participants' experiences with their own illness management and health promotion strategies used to maintain their maximum functional potential. The categories and associated themes illustrate how participants created perceptions of health within illness despite the many adversities they encountered while living with COPD.

The following section describes in length each of the categories related to the main two constructs. Each category gives information on major themes that emerged from the data.

A. Category 1: Cut off from Life

The category was derived from several participant descriptions such as: "it is just like the life I had before I got sick is totally different…, and I feel cut off from life." Overall participants described feelings of powerlessness. This comment was common to all participants in this study. This category of Cut off from Life emerged from themes found in the participant's stories about how COPD restricts their lives. One story that captured the impact of this illness for many of the participants came from a 72-year-old male, who stated, "…it cuts off my activity, cuts off my doing, and even one day sooner or later, it's going to cut my life off." The themes were collapsed by bridging, extending, and surfacing the data into subcategories, which were further collapsed to form category labels. Understanding the chronicity of COPD the participants felt powerless to change their situation. This highlights the development of a new appreciation of Health as explained in the next category Health is Everything.

B. Category II: Health is Everything.

Health is Everything emerged from participant descriptions of their health within the context of living with a chronic illness. Participants described how health meant more to them now than before with statements like "…health was number one, and health is better than wealth." This category also describes how social networks among participants and health care providers influenced health perceptions. Guided by the participants' descriptions of

health, this category emerged from three clusters of themes: Health is Worth More than any Diamond, Feel Healthy Some Days, and Feeling Connected.

Health is Worth More than any Diamond was a prominent theme within the transcripts. For other participants, health was something that you don't appreciate until you're sick. Overall, health was often described through self-reflection of personal experiences on what participants were able to physically do before their illness.

Despite the adversities, like the constantly shifting nature of illness symptoms, and the limitations placed upon participants because of their COPD, some described the feeling of being healthy. The aspect of feeling healthy differs from participant descriptions of health. Health was described in tangible terms of the ability to do things whereas being healthy was described as a personal feeling. Aspects where participants described feeling healthy within the illness were drawn from instances of the data where participants expressed perceptions of feeling healthy despite the symptoms of COPD. A 69-year-old female explained: "I feel healthy all the time except for the lung problem." She went on to say in her interview, "I don't consider myself ill. I just don't have any lungs, because otherwise I am healthy".

In summary, the category of how health is perceived within the context of a chronic illness is a complex process. Participants described their health based on their lived experiences prior to their illness. Health perceptions were measured through what their physical functioning was before the onset of COPD symptoms. Statements such as "you don't appreciate health until you're sick" are good examples of this category. Therefore, for these participants, good health meant independence, a sense of freedom to do what you desire, and **f**eeling happy and energetic. Health was not something that participants thought of daily, but as participants compared days of their illness experience, they described how they felt healthy some days. Health was often spoken of in more concrete terms such as a balanced diet, exercise, and not abusing the body such as through smoking, whereas perceptions of feeling healthy were more abstract and personal. However, perceptions of feeling healthy within the illness experience were influenced by more than personal perceptions of health. Feeling healthy was also influenced by how connected participants felt in their relationships with family, friends, and health care providers. The data demonstrates that a positive sense of connection within a relationship helped participants maintain or create a sense health within the illness experience.

In answering the first research question, the data suggest that, for this sample, illness played a central role in participant descriptions of their understanding of how Health is Everything, and, without health, "you are Cut off from Life."

The next category, Making the Best of It, describes ways participants perceived and described healing within the context of living with a chronic illness. These data answer research question one. Category III, (see Table 1) also describes practices to promote their health and achieve their maximum functional potential, which relates to research question two.

C. Category III: Making the Best of It

The category Making the Best of It emerged from participant descriptions of ways they were able to maintain a sense of understanding about living with a chronic illness. Participants described how, despite their illness, they had "… made great leaps" since acknowledging the illness. This category includes descriptions of their strong "willpower of wanting to do" their best. A recurrent trend in the participant descriptions of living with COPD was the will to keep living. Participants described how they had learned to make the best of their life despite the COPD. Common descriptions included those such as one by a 72-year-old participant with severe COPD who said: "I'm going to live to the best of my ability and do the best I can until the time comes." Making the Best of It for other participants meant coming to terms with their illness through the knowledge and understanding they had gained by living with the illness, as well as the support they received from family and friends. Not all participants were able to or desired to come to terms with their illness but still tried to make the best of their situation to maintain some form of quality in their life.

Through further analysis of the concept of Making the Best of It, participants described how they experienced a sense of personal growth with COPD. Some developed a feeling of tolerance to let go of anger or guilt about things that might have bothered them in the past. For example, one female participant stated how she learned to "… be less angry with me for having this disease" while other participants learned "…more patience than I use to have." Common to all participants was their understanding that with the diagnosis of COPD there is no physical healing or cure.

Learning to Accept the illness was important for some participants to gain an understanding about living with COPD and to keep going. This is well described by a 63-year-old female who had COPD for five years. She says "I have learned to accept it (the COPD) now that it is inevitable this is going to kill me, I am trying to take it one day at a time."

Acceptance of the illness was not necessarily important for all participants. Nevertheless, when these individuals accepted their illness, they maintained a strength or will to keep living. Contrary to this belief, a few participants felt that if they did not come to terms with their illness, this non-acceptance would provide them an avenue of hope that a cure might be possible.

In summary, the category Making the Best of It illustrates conceptual components that relate closely to Moch's [8, 9, 28] concept of health within illness. Participants described how they created a new meaning about life as well as insights into their illness experience. By gaining deeper insights, they expressed feelings of being more tolerant of what bothered them in the past, and they learned to manage their lives one day at a time. By gaining a sense of understanding about their illness, participants began to describe what living with COPD meant to them as illustrated in the next category, Living with IT.

D. Category IV: Living with It

The category, Living with It, emerged from the collapsing of themes that described participant perceptions of living with the COPD illness. The category Living with It differs from the category Making the Best of It in that the category Living with It describes the daily adversities faced by participants, while the category Making the Best of It describes how participants gained a sense of understanding about their illness. Participants spoke about not knowing from day-to-day what may transpire in their lives. For example, participants explained having "…real good days" and days they don't feel like doing anything. The uncertainties of day-to-day experiences of living with a chronic illness have been well documented in the literature [7, 40-44]. This study validates those findings by most participants stating that some days were good and some were bad. The fluctuations or ups and downs were a common pattern of the shifting nature of COPD.

The fluctuations of good days and bad days seen in COPD demonstrate the dynamic and changing patterns of individual control. Sometimes the participant felt in control and sometimes the illness was in control. Good Days/Bad Days were significant when describing a sense of control. A 70-year-old male who has had moderate to severe COPD of the past 9 years describes this phenomenon best. He stated: "Some days it seems I breathe better and I can do more. Some days all day long I just huff and puff trying to get through the day."

The category Living with IT provides further insight into research question two. This category describes how participants learned to manage their illness day-to-day and when faced with adversities associated with COPD their strategies to promote health and function such as looking ahead for better days. The last category Breaking the Cycle continues to describe practices used by participants to promote their health and achieve maximum functional potential within the context of the limitations imposed by this chronic illness.

E. Category V: Breaking the Cycle

The category Breaking the Cycle was inducted from participant descriptions of practices used to promote their health and achieve maximum functional potential within the limitations imposed by their COPD illness. This category emerged from the collapsing of themes that related to health maintenance and symptom management strategies. Participants described how they pushed themselves to do things to keep from thinking about the illness.

The strategies participants found successful in the management of their illness centered on three themes. The themes relating to knowing the limits were (a) stopping when breathing hard, (b) avoidance of environmental triggers, and (c) nutrition and weight. However, a cornerstone to the category Breaking the Cycle were participant descriptions of forgetting the illness through finding alternative activities to keep their minds busy so as to not constantly think about their illness. Forgetting the illness was not identified as a form of denial but a way to transcend the complexities of a chronic illness.

Forgetting the illness meant participants keeping active or finding something enjoyable to do. All participants felt finding something enjoyable to do outside of thinking about "being sick" helped them manage the adversities of the illness experience. A 69-year-old female who was limited in most physical activities remarked how her "brain was still active" and found pleasure in writing short stories or watching TV. "I enjoy my TV and I have some books that I read." Keeping occupied gave participants pleasure. A 70-year-old male who has had COPD for the past nine years and still tries to remain active without using his prescribed oxygen states "I feel a lot better about myself if I do a little something." For the two participants who still worked part time, work provided a reprieve from thinking about the illness. For example, a 57-year-old female participant stated "…working helps. Definitely, it keeps your mind off of it (the COPD). It keeps you busy."

Since COPD is a chronic illness that requires frequent use of medications to maintain a fine balance between breathing and not breathing. Self-management affects all dimensions of participants' attempts to break the cycle to achieve maximum functional potential. Maintaining the routine of medication as well as oxygen management was a complex process that participants approached with varying degrees of flexibility or rigidity.

VII. Discussion

Health within illness is described by Moch [8, 9, 28] as a transformational process that occurs during periods of compromised well-being where an illness may present new opportunities for personal growth. Through the analysis of participant data, five categorical descriptions emerged to support the concept of health within illness as described by Moch. However, the data also highlighted some significant differences

Through a growth process, Moch postulates persons experiencing a chronic illness can become more aware of themselves and others. In addition to the growth process, the concept of health within illness also examines the positive components of the illness experience. These experiences often promote quality of life and enhance feelings of inner self-satisfaction. Contrary to Moch's finding, the participants in this study spoke about conflicting processes including being cut off from life, and powerless. Despite these two negative experiences, they also reported being transformed, and experiencing days of feeling healthy**.**

For the participants, being sick took on significance not only because of the inherent nature of COPD, but also because many of the psychosocial processes were occurring simultaneously. These included lifestyle changes, role changes, identity transformations, and deeper insights into self-perspectives. Therefore, COPD illness experience in this study was reported holistically, which included the participants lived cognitive, emotional, and social experience. Therefore it wasn't surprising that the study participants

ascribed multiple positive and negative meanings to health, illness, and healing that differ conceptually from those proposed by Moch. As evidenced by the descriptions of the study participants, a conceptualization of health within illness should include the whole experience. The data from this study demonstrate that both positive and negative perspectives play an important role in understanding of how participants created a sense of health within their illness experience.

Participants highlighting the positive and negative aspects of the study attest to the complexity of the concepts of health, illness, and healing for persons living with COPD. The findings underline that the metaphors and symbols used by the participants to describe their experiences are unique and vary within this group. Living with a chronic illness such as COPD is a process of continual change not unlike what Moch [8, 9, 28]described in her concept of health within illness or that described today's crisis literature [20]. Similar to literature findings, study participants described how their lives were changed by their illness. They took health for granted but now view health as a precious commodity "worth more than any diamond in the world." However, participants described the negative aspects of their illness. They reported being cut off from their previous life, powerless to engage in almost any activity due to their loss of lung power. However participants did report gaining "deeper insights" about their illness and themselves.

Few studies have explored the conceptual components of health within illness beyond those of Moch [9]and Lindsey [31]. The idea of health within illness is predicated on the assumption that illness is a potential vehicle for change to occur. Traditionally, most research has focused on eliminating or fighting the illness as opposed to viewing the illness as an opportunity for growth. Moch identified four components of the health within illness concept through three phenomenological studies with breast cancer patients. These components were: (a) The illness should be seen as an opportunity, (b) there is a perception of increased meaningfulness in life through the illness experience, (c) the experience involves a sense of connectedness/relatedness through communication with others, and (d) the person gains self-knowledge through awareness of self.

Similar to the findings by Moch [28], Lindsey [31],and others [6, 7, 11, 13, 21-26, 45, 46], the participants in this study described how they found new understanding or meaning in their lives by redefining their outlook on life or in finding new meaning to the significance of their lives. For example, events that happened in the past or people who played little significance in the lives of the study participants prior to the onset of their illness were now perceived to be more significant.

Comparable to what has been described by Carter [30], Coward [27], Lindgren et al. [35], Lindsey [31],Prediger [25], and Smith [29], this group of participants described the significance of maintaining a sense of connectedness or relatedness when communicating with others. In addition, participants gain self-knowledge about how to manage their illness. They also became more aware of their bodies by finding ways to promote their health. This activity is similar to reports in other studies [6, 7, 32-35, 47]. All of these descriptions of transformations that occurred during the illness experience are similar to components identified by Moch [9] as essential to the concept of health within illness.

Despite similarities to Moch's [8, 9] components of health within illness, this group of participants described significant differences. They informed the researcher how their perceptions of health and illness were dynamic or subject to change over time. They expressed heightened feelings of overwhelming despair interspersed with perceptions of feeling healthy within the illness. Chronic illness among these study participants highlighted the constant changing of boundaries between health and illness. Presently, the definitions of health and illness used to understand chronic illness, in particular COPD, do not reflect its changing nature [48].

A number of researchers have portrayed the fluctuating nature of chronic illness [40, 41, 49-51]; however textbook definitions tend not to illustrate that sick people who are dealing with illness also have aspirations. The lived experiences of chronic illness include both positive and negative components [44]. While nursing has traditionally advocated caring for the unique needs of the individual patient, our disciplinary research has focused on explaining illness within the context of physiological, psychosocial and behavioral sciences rather than attempting to understand how individuals find meaning in their illness experience [44]. The importance of this study is that it recognizes that the meanings of health within illness are always dynamic and constructed within the context of the individuals' lived experience. This will assist in tailoring care to better meet individual care needs, both negative and positive, as well as support transformational processes.

Author Profile

Dr. Bruce Leonard and Dr. Michele Clark are Associate Professors at the University of Nevada, Las Vegas School of Nursing. Dr. Leonard's research background has focused on self-management strategies used by persons with chronic illnesses such as COPD. He is a certified Family Nurse Practitioner. Dr. Clark is the Chair of the Psychosocial Department and the PhD Program Director. Dr. Clark's research has focused on caregiver burden among persons caring for persons with chronic illnesses. She is a certified Marriage and Family Counselor.

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